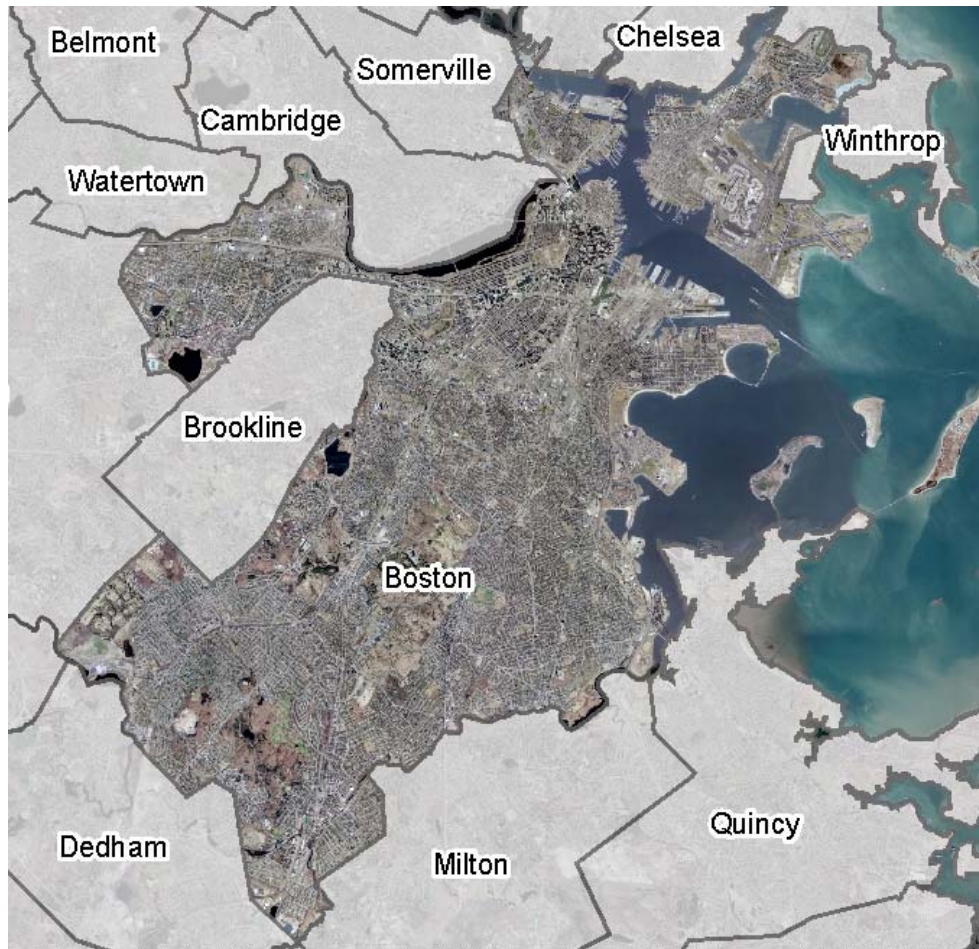


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The Incidence and Prevalence of Systemic Lupus Erythematosus  
(SLE) in Boston and Environmental Factors

**INFORMATION BOOKLET**



Massachusetts Department of Public Health  
Center for Environmental Health  
Environmental Epidemiology Program

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**Q1. What is lupus?**

**A.** Systemic lupus erythematosus (SLE) or lupus is a condition of chronic inflammation caused by an autoimmune disease. Autoimmune diseases are illnesses that occur when the body's tissues are attacked by its own immune system. Lupus affects many parts of the body. Symptoms may be mild, moderate or severe and most often affects women between the ages of 15 and 45.

**Q2. Are there specific populations at higher risk of being diagnosed with lupus?**

**A.** Yes. Occurrence is 3 to 4 times higher in Blacks than Whites. Latinos and Asians also have higher prevalence rates than Whites. Blacks and Latinos have a slightly younger age of onset and more severe disease than Whites, with Blacks having a higher mortality rate.

**Q3. Why was lupus surveillance conducted in the City of Boston?**

**A.** The lupus surveillance effort was conducted in response to a line item directive in the Massachusetts Acts of 2001. The line item directed the Massachusetts Department of Public Health (MDPH) to design and implement a surveillance system to better understand the prevalence and patterns of individuals diagnosed with lupus in Massachusetts.

**Q4. What is the lupus surveillance system or “registry”?**

**A.** The surveillance system designed allowed MDPH to determine the number of individuals who were residents of Boston and who had been diagnosed with lupus. Due to limited resources, MDPH focused the surveillance on the City of Boston.

**Q5. How did MDPH collect information on individuals diagnosed with lupus?**

**A.** The primary method of identifying Boston residents diagnosed with lupus was through the review of in- and out-patient medical records of eleven hospitals determined to be most

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likely to serve Boston residents diagnosed with lupus. A review of clinical lists from Boston community health centers and a survey of private rheumatologists statewide was also conducted to determine whether additional cases could be found.

**Q6. Which residents were included in the lupus surveillance effort?**

**A.** The eligibility criteria for inclusion in the surveillance effort were as follows:

- The individual was a resident of the City of Boston during the time period October 1, 2003, through September 30, 2004
- The individual had at least one office visit or a hospitalization between October 1, 2003, and September 30, 2004
- The individual was diagnosed with SLE between January 1, 1999, and September 30, 2004

**Q7. What other activities were carried out to address concerns over lupus and environmental factors?**

**A.** Two investigations have been carried out over the past several years evaluating potential relationships between lupus and environmental factors in Boston.

- A. Brigham & Women's Hospital (BWH) researchers, in partnership with MDPH and the Women of Courage, explored the possible relationships between residents with a diagnosis of lupus and environmental factors in Roxbury, Dorchester, and Mattapan (RDM). This effort was aimed at determining whether certain genetic factors in combination with environmental exposures might increase the risk of developing lupus
- B. MDPH sought and received funds from the U.S. Centers for Disease Control and Prevention (CDC) to establish health and environmental databases in MA. In Boston, MDPH explored the possible relationship between lupus and

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opportunities for environmental exposure throughout the City of Boston.

**Q8. Why were environmental factors explored?**

A. The recent medical/scientific literature suggests that petroleum distillates, mercury, silica and chlorinated hydrocarbons may be associated with SLE and other undifferentiated connective tissue diseases.

**Q9. What environmental data were used by MDPH and Brigham & Women's Hospital to evaluate the possible role of environmental factors?**

A. The primary source of environmental data for the MDPH surveillance project and the RDM study was derived from an environmental database maintained by the Massachusetts Department of Environmental Protection (MDEP). MDEP regulates all hazardous waste sites within the Commonwealth of Massachusetts as a result of Massachusetts General Law, Chapter 21e. A database of the sites in Boston was generated by MDPH for purposes of the two studies described earlier.

**Q10. What environmental data are contained in the 21e database?**

A. The MDEP database contains up-to-date information concerning the status of each hazardous waste site. However, the actual environmental data are, for the most part, limited to information collected during the initial stages of when a release has been identified at a particular site.

**Q11. What information did the MDPH environmental database include?**

A. MDPH identified sites from the MDEP database that had the presence of petroleum distillates and other contaminants mentioned in question #7 of this information booklet. These sites were queried by type of site and chemical spilled, as well as, location for all

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projects conducted by MDPH and BWH researchers in collaboration with the Women of Courage.

**Q12. Are rates of lupus for the City of Boston unusual?**

**A.** No, the incidence and prevalence of lupus for the City of Boston overall did not appear unusual compared to national data. In addition, the prevalence among females was about nine times that in males, a finding consistent with the scientific literature.

**Q13. Did the rates of lupus appear unusual in Boston neighborhoods?**

**A.** The neighborhood of Roxbury had the highest prevalence, which was statistically significantly higher than expected based on Boston rates as a whole. However, it is important to note that this neighborhood has a greater proportion of individuals at higher risk of developing lupus (i.e., Blacks, Asians, and Caribbeans) compared to other neighborhoods.

**Q14. Did MDPH determine that environmental factors might be associated with lupus?**

**A.**

- MDPH's exploratory review suggested that the incidence of lupus appears higher in neighborhoods with more hazardous waste sites containing petroleum distillates per square mile; however, the incidence may also be higher in these neighborhoods because of greater proportion of residents at higher risk of developing the disease.
- The analyses suggest that historical opportunities for exposure to industrial operations rather than to the waste sites themselves may have played some role in the patterns of lupus observed in Boston neighborhoods.

**Q15. What is the current status of these hazardous waste sites in Boston today?**

**A.** According to MDEP records, the majority of the hazardous waste sites evaluated for both projects was cleaned up or are thought to present lower risk of exposures, due to stringent

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requirements in place today that direct more immediate responses to releases of oil or hazardous waste.

**Q16. What were the major findings of the RDM Collaborative Project?**

**A.** The research conducted by BWH in partnership with the Women of Courage and MDPH suggests that certain genes in combination with living close to hazardous waste sites that contain petroleum distillates may have played a role in increasing the risk of earlier age at diagnosis of lupus among African-American women in RDM. However, researchers believe that this finding must be found in other studies to more clearly understand the role of this gene and environmental exposure in the diagnosis of lupus.

**Q17. If I live closer to a hazardous waste site does it mean that I will get lupus?**

**A.** No. The BWH researchers found that living near hazardous waste sites prior to a lupus diagnosis was NOT associated with lupus diagnosis. Rather, having one of the genes AND living near hazardous waste sites had a modest increased risk of an earlier age of diagnosis of lupus.

**Q18. If I have the GST gene, does this mean I will get lupus?**

**A.** No. In the RDM study, over half the women without lupus and who served as a comparison group had one or more of the GST genes under study, and they did not have lupus.

**Q19. How likely is it that I have one of these abnormal genes?**

**A.** Among the individuals who participated in the BWH study, about 62 percent of Black participants had GST genes, while about 65 percent of non-Blacks had the GST genes. The percent of participants who had the GST genes was similar between Blacks and non-Blacks.

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**Q20. What is the overall conclusion of the efforts of the WOC, the Brigham and Women's researchers, and MDPH with respect to lupus?**

**A.** It is not clear what risk genetics or exposure opportunities to environmental pollutants may play in the occurrence of lupus among Black women. The RDM research suggests gene-environment interactions may play a role in an individual having an earlier diagnosis of lupus. Possible relationships between lupus and hazardous waste sites containing certain chemicals is likely related to past industrial practices in areas now known as hazardous waste sites, but not with living in these neighborhoods presently.

**Q21. What recommendations were recommended for follow-up?**

**A.** The following activities are recommended as follow-up activities:

1. MDPH should partner with community health centers and hospitals to provide clinical training and circulate an SLE screening tool to ensure prompt diagnosis and treatment.
2. Increase community awareness:
  - Summarize study results for popular use
  - Hold community education forums with Women of Courage and other community-based coalitions
  - Train community members to do health education on SLE and provide stipends for them to do outreach and education
3. Hold meetings with city officials to discuss broader policy implications
4. If adequate funding becomes available, future surveillance of SLE should focus on prospective case finding (that is, as patients are diagnosed) and include case ascertainment from neighborhood health centers and private rheumatologists rather than hospitals alone.

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**Q22. Where do I go if I have questions about these studies or lupus in general?**

**A.** You can contact the MDPH Center for Environmental Health at 617-624-5757 if you have any questions about these lupus projects. Copies of the MDPH final report and of the RDM study conducted in collaboration with the WOC and BWH's journal article are also available at [www.mass.gov/dph/ceh](http://www.mass.gov/dph/ceh).